Arizona Department of Health Services
Office for Children with Special Health Care Needs
Integrated Services Grant

ISG-Cultural Competency Committee
6-21-06
Meeting Minutes

Attendees: N. Burton Attico, MD; Kristine Buchanan; Renaldo Fowler; Kymyacta Gaines, Gwenda Gorman, Tom Kirsch, John Molina, MD; Ramona Quihuiz; Rona Rehman; Kim Russell; Samantha Tunis; Denis Viri; Jill Wendt

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
Pre-Meeting Notes		The ISG Cultural Competency Committee welcomed Kymyacta Gaines and her daughter Khalia Gaines; Kristine Buchanan (a Committee member) and her twin sons Joshua and Jordan. Kristine and Kymyacta; with Quest to Cure Sickle Cell Anemia Foundation (ISG partner). They will give a special presentation on their organization and the programs they have initiated to help children with the disease/trait.	*Visit www.questtocure.org to learn more about Sickle Cell Anemia
Welcome and Introductions	Dr. Molina	Dr. Molina welcomed all the Cultural Competency members to the 6-21-06 meeting. We are especially excited to have Kristine and Kymyacta for a Special Presentation on Sickle Cell Anemia. We are also happy that the children, Khalia, Joshua and Jordan could join us too.	
	Mrs. Wendt	Let me give you an update on committee membership. Victor Flores is no longer at CPSA. CPSA will continue to be involved as the Regional Behavioral Health Authority for Southern Arizona. They will be sending a representative to our future meetings, once they have filled the position. Gustavo McGrew left ValueOptions, however he may be involved in the future in this committee. Both Lillie Sly and Rick Ybarra got tied up at the last minute and won't be in	

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		attendance today.	
Review of 5-17-06 Meeting Minutes	All	The Committee reviewed the meeting minutes of 5-17-06. Typographical errors to correct related to Rick Ybarra, not being called Rich; and Jill Wendt is Mrs. Wendt, as opposed to Ms. With those corrections, the 5-17-06 minutes were passed by consensus.	*Minutes from the 5-17-06 meeting were approved with corrections.
Reporting to the Executive Task Force Update – May 2006 Status Reports	Mrs. Wendt	*(refer to status report in handout packet)* Advised the committee that the May 2006 Status Report for Cultural Competency went to the Task Force at their May 24, 2006 meeting but the time was limited at that meeting, and the report was tabled for the next meeting in August. So an update from our committee will be given at that time. Our report addresses the priorities that the committee had discussed and given consensus on. The Status Report form/format is the reporting mechanism we use to formally report to the Task Force. You can see that the goals and objectives are defined. This outlines possible strategies and activities. It tells of our progress with tasks. I would like to have this posted to our Website if everyone is satisfied with it.	*Committee agreed by consensus that the May 2006 Cultural Competency Status Report to the ISG Task Force could post to the Website.
		I did want to share with this Committee that I am taking over the oversight of the Integrated Services Grant. The grant is going into its second year. I am reviewing all documentation right now and getting up to speed on the different activities that the ISG Committees are involved with. By our next meeting, I will have a summary document that reviews Year One and shows everyone what the Committees are doing, where each Committee is at, including our committee. This will help everyone get a better picture of the grant.	*Provide copy of the summary document in the next meeting.
	Dr. Molina	One of the documents under consideration is the Community Survey. The idea of the survey was to get an assessment of the community needs and organizations doing work with children with special health care needs. In the last couple meetings we have had a draft of the survey circulating. We had asked for the members to review it and give us feedback. If there weren't any more ideas, we want to move forward.	
	Mrs. Wendt	We still want comments on this if you think this is a good tool. We also want this document to go through the ISG Parent Action Council for their okay before we go forward it. This is a type of tool that can cross over committees and be used in different areas. Then we can decide how we want to use this, what we want to	

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		accomplish, how do we want to implement it.	
	Dr. Molina	I am hoping that the information that we get from the survey will help us identify some of the agencies, parents, or action groups within the communities that we can work with to develop the strategies that we have already outlined. We want to get information from the ground up. This helps us be a bit more realistic and practical in the goals that we want to undertake and accomplish. This will also identify opportunities and people to network with. So we look forward to your thoughts.	
Special Presentation: Quest to Cure / Sickle Cell Anemia	Kristine Buchanan, Kymyacta Gaines, Quest to Cure	Kristine Buchanan, Executive Director of Quest to Cure and Kymyacta Gaines, Project Specialist, distributed a paper copy of the presentation to the committee. The Quest to Cure organization is a non profit organization dedicated to helping children with sickle cell focus more on life not pain, and to heighten awareness as it relates to sickle cell disease while bringing our sickle cell communities together. The goals and objectives of the organization are: 1) Create resources and outlets for families with Sickle Cell Disease -Offer a 7 day summer camp program for children with sickle cell which caters to their needs as it relates to sickle cell disease by July 1, 2006; -Develop a trained volunteer group of 10 to begin outreach services not limited to home schooling, hospital visits, respite and child care or home relief for care givers of children with sickle cell by July 1, 2006; -Identify and contact programs which support newborn screening and adult sickle cell trait testing by January 1, 2006; -Establish an open communication/link between sickle cell patient, emergency room doctors, hematologist, and pediatrician by September 1, 2006. 2) Educate and enhance awareness to families that are coping with a loved one with the disease. -Establish a monthly community based support group and	*Visit www.questtocure.org for more information on the Sickle Cell Advocate Program at Quest to Cure *Link on www.azis.gov for Quest to Cure under "Links to Grant Partners".

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		quarterly informational conference to the public to heighten sickle cell awareness by April 1, 2006; -Publish and distribute educational materials as to cause/prevention/history of sickle cell disease by June 1 2005; -Conduct a yearly health fair at local participating churches, schools and/or colleges by January 1, 2006. 3) Help find a cure for Sickle Cell Disease -Establish a fund to distribute a yearly contribution to the national laboratories conducting new technologies and research for the cure of sickle cell disease by December 20, 2006.	
<u>Special Presentation</u>: Quest to Cure / Sickle Cell Anemia (con't)	Kristine Buchanan and Kymyacta Gaines	The Quest to Cure Summer Camp is taking place from July 9, 2006 through July 13, 2006. The 2006 sickle cell summer camp program is a four-day out of state road trip. The camp will cater to sickle cell children between the ages of 7 and 16 years of age. Children with sickle cell disease are unable to participate in ordinary summer camps due to their limitations. Traditional summer camps ordinarily offer hiking in high altitudes, swimming, and many other activities which children with sickle cell are unable to participate in without a sickle cell awareness specialist to monitor	*Quest to Cure Summer Camp is July 9, 2006 through July 13, 2006
		The Sickle Cell Advocate is a new initiative set forth by Quest to Cure in collaboration with: ADHS, AHCCCS, ADHS-CRS, Hematologists, Community Health Professionals and Primary Care Physicians. • *The Sickle Cell Advocate"* is a *USB Flash Drive* device that will personalize sickle cell sufferers' medical information. USB flash drives are compact and easy to use devices that are similar in use to your computer hard drive. USB flash drives slip into your pocket, conveniently around your neck or on a keychain for ultimate portable storage. USB flash drives finally fulfill the real promise of the digital age: complete freedom and mobility. • The information stored on*"The Sickle Cell Advocate"* flash drive will be important in assisting health professionals to provide the best appropriate care for sickle cell patients in an urgent/emergency situation. • The *"The Sickle Cell Advocate"* will serve as a guide to the patient's sickle	

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		cell medical needs. • Local hematologists and primary care physicians confirming that this is a sickle cell disease patient and sees a doctor regularly will endorse the *"The Sickle Cell Advocate"*	
<u>Special Presentation</u>: Quest to Cure / Sickle Cell Anemia (con't)	Kristine Buchanan and Kymyacta Gaines	Main issue sickle cell sufferers face in crisis situations • Trying to convince the medical field how bad they need medical attention. The Sickle Cell Advocate is very important in specific Emergency Room situations whereby a sickle cell patient will seek help at an ER and be turned away, not believed, not treated, or made to wait while in crisis. Simply because the medical staff (nurses, interns, doctors, staff) do not believe that the patient has sickle cell or is in dire need of medical assistance. The prevailing interpretation at hospitals, ERs, and even doctor's offices is that sickle cell patients are seeking drugs. It is a re-occurring problem. Unless the records are within reach to review, to seemingly prove the disease, the medical professionals and current medical system will assume the patient is a drug addict and treatment is delayed or not even given. The Sickle Cell Advocate program supplies these patients with their medical information on a computer jumpdrive so there should be no hesitation, *on site,* with receiving proper medical care. <u>Other notes of concern with ER and hospital staff:</u> -The nature of emergency room care can mean that patients with vaso-occlusive pain crisis may wait for long periods of time for evaluation and treatment. -Patients frequently are under medicated, because an ED physician may (reasonably) be cautious with an unfamiliar patient. -Issues regarding proper pain medication often evokes confrontation between patient and staff. Hostility develops on both sides. -Consequently, almost as a matter of course in a crisis situation, the patient's frustration increases with the rising pain levels.	

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		-The interaction of an often-harried ER physician, and a patient with sickle cell disease who has frequently waited hours to be seen, is not congenial. -The rotating nature of the staff in most emergency departments means that patients with sickle cell pain crises often see different providers with each visit. -The likely-hood of an admitting nurse or attending doctor remembering the sickle cell sufferer, or wanting to treat them again is unlikely, due to their opioid needs.	
Special Presentation: Quest to Cure / Sickle Cell Anemia (con't)	Kristine Buchanan and Kymyacta Gaines	Other programs offered by Quest to Cure: Mentor Me Program The mentor me program was created to help enhance the life of all people who suffer from sickle cell disease. Quest to cure's goal is to partner older sickle cell suffers with younger sickle cell patients. Our objective is to teach growth and developmental education, while building a youth community support system. The average sickle cell female puberty is usually delayed by several years. Menarche (beginning of the menstrual period) is also delayed. Males with sickle cell anemia maintain a lower average height and weight than those males with normal hemoglobin. This lower than average height and weight continues until late adolescence. Puberty is usually delayed by several years also. It is important to reassure the adolescents that they will eventually catch up with their peers.	
		Bedside Buddies Volunteers visit children/adults in the hospital. Bedside buddies will bring lunch, flowers, story time and parent relief for children and any personal items the patient may need.	
		School Success Program Sickle Cell children could potently miss a lot of classroom time; Academic grades among patients average less than C, even in children with a low frequency of hospitalization (averaging 17 days a year). Our program goal is to make contact with child's school to insure all needed make up work is collected. A trained SC advocates can/will sit and helps with homework and return finished assignments to	

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		teacher at negotiated time.	
Special Presentation: Quest to Cure / Sickle Cell Anemia (con't)		Support Group Referral Service In assessing the seriousness of this disease, no one should underestimate its emotional and social impact. For the family, there is nothing more heartbreaking than to watch their child endure extreme pain and life-threatening medical conditions. The patient endures not only the pain itself but also the emotional strain from unpredictable bouts of pain, fear of death, and lost time and social isolation at school and work. Quest to Cure serves as a vehicle and referral service to support groups and social workers who are dedicated to providing emotional and psychological care to sickle cell sufferers and their families / caretakers.	
		Community Awareness and Monthly Family Fun Days Education and public information are the most effective tools for increasing awareness of sickle cell disease. With television news and radio waves flooded with information on more popular health issues, sickle cell disease has been ultimately placed on the back burner. Quest to Cure has created an avenue where the community, supporters and suffers can come together to learn about sickle cell disease and interact with children and youths who suffer from sickle cell through; community activities such as picnics, health fairs, pizza party's and family night out at the drive in. Quest to Cure volunteers distribute knowledgeable materials and make themselves available for any questions the community may have regarding sickle cell disease.	
Questions/ Discussions	Group	The committee members discussed areas of concern related to sickle cell patients and the medical profession and systems of care. Points noted: *Do other states have a model in place?	*What other states have Sickle Cell programs or centers in place & what do they do? (Atlanta, New York, Detroit)
Questions/ Discussions (con't)		*Emergency Room issues – how professionals/staff assume that the patients are seeking drugs or are a drug addict. How the "poking for blood" has to be done by an experienced staff member and not a novice that will poke 4 to 5 times before drawing the blood. *Are medical professionals being taught about sickle cell and to what degree? It was noted that sickle cell is taught in the first two years of medical training and that the pathology is learned. But on site training is the best.	

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		*Do the professionals at a hospital really know the symptoms are and what "a crisis" is? *Legislation in 1980 helped children with sickle cell but legislation has to do more with young adults. Laws must be revisited. *EPSDT has no data gathering for sickle cell *The education of sickle cell anemia has to go higher up, to administrators. Re-educate. *CPS getting wrongly involved in the family unit by assuming mother of sickle cell children are neglecting their children or somehow "making the children hurt". The behavior of "non acceptance", that this disease is real; is the stigma that surrounds sickle cell anemia. This behavior is clearly evident within the medical profession and state agency(s). *Does the NewBorn Screening Program notify parents correctly? Upon notifying the parents, etc. –are resources distributed or networking done with the parents? Does NewBorn Screening pass on this information to another agency for coordination of care? Or does HIPAA not allow it? *HIPAA and FERPA block information from being obtained at school It was noted that the schools do release information to the parents and parents can become advocates. *What services do sickle cell children get at school? *The United Way Community Referral Book is a good resource for networking organizations and agencies. *Insurance coverage	
Resources		The following are state specific websites for review: www.state.in.us State of Indiana Dept of Health Sickle Cell Program www.sicklecelldisease.org Sickle Cell Disease.org www.sicklecelldisease.org/members/index.phtml - Member lists throughout USA by state www.ascaa.org American Sickle Cell Anemia Association www.ascaa.org/support.asp - Supports Groups	

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		www.state.nj.us New Jersey Department of Health and Senior Services www.sicklecellnm.org The Sickle Cell Council of New Mexico, Inc www.ohiosicklecell.org Ohio Sickle Cell and Health Association www.afmc.org Arkansas Foundation for Medical Care www.vahealth.org Virginia Department of Health www.utdallas.edu University of Texas at Dallas Sickle Cell Research Center www.gtpsicklecell.org Got the Power Sickle Cell – Florida www.scdfc.org Sickle Cell Disease Foundation of California www.idph.state.il.us Illinois Dept. of Public Health www.scanca.org Sickle Cell of the National Capital Area, Inc (Wash DC) www.mcg.edu Medical College of Georgia	
Next Meeting		**Wednesday, July 26, 2006 1pm-3pm ADHS Bldg.; Room 345A**	